

House of Representatives
State of Michigan
Lansing, Michigan

May 22, 2006

To: Members of the House of Representatives:

Eleven years ago, as a young vibrant woman of forty-four, I was diagnosed with Rheumatoid Arthritis (RA), Fibromyalgia, and Osteoarthritis. The RA is the most serious and is a systemic disease that affects the entire body. An abnormality in the body's immune system causes it to work improperly and leads to inflammation in the lining of the joints and other internal organs. Chronic inflammation can lead to joint deterioration, significant pain and limited movement, and even heart disease. My doctors prescribed corticosteroids and methotrexate, a chemotherapy drug that when used in lower doses is an effective treatment option for RA. Initially, this therapy regimen curbed the disease progression and I was able to manage the pain. However, after several years of taking methotrexate at increased doses, my liver could no longer handle the harsh side effects of the drug. Accordingly, the doctors were forced to seek another alternative.

Over the course of the next three years, I was treated with Vioxx, a nonsteroidal anti-inflammatory drug (NSAID) which proved to be successful in managing my arthritis pain. However, this drug became unavailable to me, when drug maker, Merck, removed it from the marketplace. As a result, my options became more limited, forcing me to try another NSAID which has not helped at all.

Recently, a new class of medications called biologic response modifiers (BRMs) has emerged. These drugs target the source of inflammation and can actually stop the disease progression and, in some cases, have proven to initiate a long-lasting remission. My physician has recommended I start one of these drugs. Unfortunately, I can't afford any of them, because they cost at least \$1,125 a month. I do not have prescription drug insurance because, at \$1,000 a month, I cannot afford it. My arthritis has gotten progressively worse and I live in constant pain. The easy answer to my problems would be to apply for disability. If I was on disability, Medicaid would pay for the biologic response modifiers (BRMs.) But I am not ready to give up. I would rather be a contributing working member of society than be forced to retire and not work at all.

My husband and I are small business owners and employers; both contributing to Michigan's economy. I own Figure Eight Fitness, a workout facility for women, and my husband, Hubert, owns Metro Auto Body, in Mt. Clemens. Between our two companies, we have employed thirteen people over the last thirty-two years. Despite our contribution to our community's economy, I cannot afford to add prescription coverage to my current insurance plan, nor can I afford a drug that has proven benefits in the treatment of rheumatoid arthritis. It is extremely frustrating to know that there's a drug available that could help me, yet, I cannot afford it.

Sherryl Cook
37412 Castleton Dr.
Sterling Hts., Michigan 48312

Although I can't do anything about the high cost of prescription drugs, I can take advantage of the programs offered by the Arthritis Foundation. They have a series of exercise programs that are designed to help me take control of my arthritis. I recently completed training to be a certified Arthritis Foundation program instructor and currently teach the *Arthritis Foundation Aquatic Program*, and an exercise program known as *PACE*. While there is no doubt that drug therapy would significantly decrease my pain and slow the disease progression, these exercise programs have helped me improve my quality of life by increasing my range of motion, flexibility and stamina.

I am sorry that I cannot be here today to ask you in person to support the Arthritis Prevention and Control Act for Michigan. I hope that my story will help you understand how very important it is for people with any of the painful forms of arthritis to believe and hope that their elected officials "get it"... that our legislators understand how very important it is to have access to programs that help us maintain quality of life and to find ways to continue to work and be productive members of the Michigan population.

Sincerely,

Sherryl Cook
Phone: 586-855-1989

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May 2, 2006

Laura Berman

Woman lives with pain but works to make a difference



At Sherryl Cook's exercise studio in Sterling Heights, the clients have no illusions about morphing into Angelina Jolie -- or even Christie Brinkley -- in six months.

That thin, determined-looking woman pacing on the treadmill has multiple sclerosis. And that elderly woman walking out the door recently had knee replacement surgery.

Cook was diagnosed 11 years ago with rheumatoid arthritis, a disease that attacks relentlessly, but not always consistently. Every morning when she awakens, she monitors the day's symptoms the way most of us tune in to the weather.

"Will it be ice, heat, a shower? Before I even put my feet on the floor, I am thinking about what I can probably do, how to handle it, that day," says Cook, who keeps her hair cropped and dresses for work in comfortable sweat clothes.

Drugs are too expensive

The exercise studio is itself a health strategy: One of her early post-arthritis discoveries was the power of exercise to stave off the disease -- both physically and mentally.

There are drugs that might help. But "they're way too expensive, so I don't think about them."

She winces at this. The subject is uncomfortable because, day to day, Cook puts the possibility of relief from her symptoms out of mind.

Although her disease has grown severe enough that she could probably prove herself permanently disabled, she does not want to stop working. She wants to be a contributor, a worker bee.

But still.

Her own medical insurance, a \$1,200-a-month Blue Cross Blue Shield policy she and her husband share, is basic, lacking prescription drug coverage. And the most powerful arthritis drugs, like Remicaid, are prohibitively priced -- more than \$1,000 a month.

Her 77-year-old father, who was diagnosed with the same disease after she was, took Remicaid. "It worked great for me," Richard Wallace tells me. He has Medicare coverage that pays for drugs.

'What I have is exercise'

The health care "system" isn't any more consistent, or uniform, than Sherryl Cook's varying arthritis symptoms.

"I try not to even think about the relief those drugs might bring me," she says.

She's talking to me only in the hope of raising awareness about arthritis and the need for therapies and, even, a cure.

Two years ago, she and her husband invested in the Figure & Fitness studio, building and equipping it themselves.

She teaches water aerobics. She walked a marathon in Orlando, Fla., two years ago because, she says, "I have no run left, but I can still walk." She speaks at retreats and when the Michigan Arthritis Foundation calls.

"I decided not to sit back and let this disease take its course," she says. "What I have is exercise."

Hers is a tough call. She's opted against declaring herself disabled to get medicine that can offer relief.

Instead, she works and lives with pain, taking comfort from the knowledge that she's making a difference in the world.

You can reach Laura Berman at (248) 647-7221 or lbberman@detnews.com.

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May 18, 2006

To Whom It May Concern:

I am a local pediatrician in the Lansing area for 27 years. In that time I have seen and cared for many children with Juvenile Rheumatoid Arthritis.

Last year I was asked to participate in an expert panel whose main objective was to create the critical elements of care for Juvenile Arthritis which is a document to help clinicians to diagnose this difficult condition and help them to organize appropriate therapy and follow up. It is clear that the sooner this condition can be diagnosed and aggressively treated the better will be the long term prognosis.

The above effort was supported by money from the State to help care for this needy group of children as there is clearly a shortage of rheumatologists in Michigan. Therefore, many pediatricians and primary care physicians will take on this very critical responsibility. It was therefore imperative that they have the state of the art information to do so.

We also realized through this effort that there are many resources through the Arthritis Foundation that parents can utilize to help them connect with other families that have already gone through similar crises. This foundation also provides valuable resources which can help educate families to care for and advocate for their children.

Please continue to financially support this foundation and the valuable resources that can help physicians more optimally care for these very sick children.

Sincerely,

Mark Takagishi, M.D.

